



CASE STUDY

Digital Ethnography for Patients with a Rare Disease and Their Caregivers

Business Objective

A ThinkGen biopharmaceutical client was developing a medication for treatment of two rare diseases, with launches for both indications within two years. The brand team for the medication was seeking to deepen its understanding of the emotional realities of patients to inform messaging and other commercialization activities.

The ThinkGen Solution

ThinkGen has extensive knowledge of how patients with severe, rare diseases are often inhibited from becoming potential respondents due to the inconvenience of in-person IDIs (scheduling, traveling, etc.). For this reason, ThinkGen chose a methodology that allowed participants to respond to inquiries at home, in their own time, over a series of days, which allowed us to capture deeper insights and produced user-generated content more closely tied to the emotional experience related to their disease.

The ThinkGen research team recommended the usage of its digital ethnography methodology, featuring EpiphanESM, which consisted of five days of ethnographic tasks, activities and exercises, moderated in real time by a senior ThinkGen researcher. Ethnography activities were conducted via a user-friendly online platform in local languages. Each day's activities took 60 min to complete and could be completed in one sitting or in separate sessions throughout the day. The five-day ethnography was segmented into the following themes:

- Day 1: Introductions & Life Experience
- Day 2: Diagnosis Journey
- Day 3: Treatment Journey
- Day 4: Disease Support
- Day 5: Reflections & Future Goals



AT A GLANCE



Methodology

Digital Ethnography featuring EpiphanESM



Stakeholders Recruited

Patients with a rare disease and their caregivers



Countries

US, UK, Italy



Therapeutic Area

Rare disease



ThinkGen Client

Biopharmaceutical company



Results

Because of the timing of this project, two years before launch—when many behavioral and emotional insights hadn't yet been researched—this approach was ideal. The emotions of the patients unveiled through the research were novel to the brand team. The user-generated, multimedia output helped to further illustrate the respondents' emotions at various milestones and junctures of the patient journey. This provided further color to the nuances of the experiences of patients with these rare conditions, as well as their caregivers.

The EpiphanE structure, with its ability to generate insights for larger samples simultaneously, allowed ThinkGen to field 31 patients within a five-day time frame. This agile research process allowed for tighter turnaround findings for the client compared to a traditional IDI methodology.

The study illuminated for the client this rare patient population's emotional peaks and valleys, providing critical insight for eventual support programs, future offerings, and other communication initiatives. The client benefited by gaining the ability to dispel several assumptions about the rationale for certain patient behaviors.

Additionally, the client gained insight into the actual language patients use to describe various aspects of their experience. For example, before the study, the client doubted that patients used a specific term to describe a disease exacerbation. But, through the social listening and language tagging capabilities used within this study, ThinkGen was able to reveal which terms patients used and in what context. This enables the client to more genuinely reflect the realities of actual patients in the commercialization efforts in development.

It is always critical to this type of study to consider the general energy level of the patient population. Thus, the programming guide for this project was deliberately orchestrated to ensure patient comfort was a primary objective. ThinkGen was able to design an EpiphanE programming guide to allow for 60 min of daily activities. Any longer would have been too much for these patients. (For a different project—with a sicker, more fatigued patient population—the programming guide was shortened to 15 min of daily activities.)

SUMMARY

ThinkGen took this study beyond just an enhanced online questionnaire version of a digital ethnography. This study provided deep, daily engagement from a senior moderator, which resulted in better rapport as compared with an in-facility depth interview. Due to the nature of the concurrent moderation, ThinkGen was able to maintain that intimate level of moderator engagement, while also completing 31 multi-layered “interviews” within a five-day window.

With EpiphanE, the study provided the client with its first exposure to the profound emotions associated with the milestones of the disease. Through this unique methodology, the client not only learned what the patients' emotions were, it was able to see how the respondents characterized their own emotions through patient-generated art and other types of visuals, delivering a richer understanding of patients' “visual neighborhoods.” By conducting the study two years ahead of launch, the client is now enabled to make informed decisions while planning the launch, which will ultimately result in a more successful launch.

